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2. Chronic disease self-management: A pilot training program for people with chronic conditions

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In Australia, chronic disease accounts for roughly 80% of the total disease burden. More than $34 billion or 70% of Australia's total health care expenditure is spent on this growing area.

Many of the serious long-term illnesses experienced by Australians are preventable. These include cardiovascular disease, cancer, diabetes, asthma, arthritis and musculoskeletal conditions. Additionally, the patient can often delay the progression and avoid complications of a condition by changing their lifestyle.

Disadvantaged groups, including the elderly, people from poor socioeconomic backgrounds, Indigenous Australians and people living outside the major urban centres, are most likely to be affected by chronic disease.

The Sharing Health Care South Australia (SHCSA) project was established to determine whether community-based patient education and support programs could be implemented successfully. The study also considered whether patient and provider participation leads to improved patient self-management skills and improved quality of life for people with chronic and complex conditions.

Participants were involved in formal care planning and goal setting in partnership with their general practitioner (GP) and local service providers. They were also offered access to a six-week peer-led chronic disease self-management program modelled after the Lorig Stanford program. This training sought to build patients' skills to not only understand and manage their condition better, but also to negotiate the health care system with more confidence.

The study found that helping people to understand their chronic conditions improves their ability to manage and deal with symptoms, and results in decreased hospital and GP visits.

Relevance to rural and remote health

Australians living outside the large urban centres experience poorer health than their metropolitan counterparts. Rural Australians spend more time in hospital; they have higher mortality rates and lower life expectancy. Mortality statistics show that death rates in regional and remote areas are between 10% and 70% higher than in major cities.

Life expectancy decreases with increasing remoteness. People living in rural areas are expected to die a year or two before those living in large urban centres, while people in the most remote areas have a life expectancy of up to seven years lower than city dwellers.

People in regional and remote areas are also more likely to report an acute or chronic injury, to drink alcohol in harmful quantities, and to be overweight or obese. Compared with those in major cities, people in regional and remote areas are also less likely to report very good or excellent health. Males living in outer regional and remote areas are also more likely to show increased levels of psychological distress and are more likely to commit suicide.

And the picture grows bleaker still. Studies of socioeconomic risk factors show that rural Australians are less educated, have lower incomes, are more likely to be unemployed, and are more likely to engage in unhealthy behaviours than their city counterparts — all of which are associated with poorer health outcomes. People in rural and remote zones also have less access to health services compared with urban counterparts, indicating a need for services and strategies that support people to self-manage their health.

Chronic disease self-management (CDSM) and self-management support (SMS) are integral to health care and particularly so in rural areas where access to health services is often limited.

Despite the importance of addressing chronic disease, experience has shown that many rural health professionals lack an understanding of CDSM and SMS. GPs in particular have been difficult to engage. This is because the conceptual model for CDSM and SMS does not fit easily with existing practice models and structures and many GPs are reluctant to make changes in the absence of demonstrable clinical or financial benefits.

Case studies are needed to demonstrate the potential of the CDSM approach in rural Australia if GPs, other health professionals and patients are to be convinced to adopt it.

The research

This project had several parts. A community reference group was established from the outset to provide advice and community leadership for the project and also as a vehicle for community development and capacity building in CDSM.

Project participants included participants with chronic and complex conditions (diabetes, asthma, arthritis, cardiovascular disease and osteoporosis). Non-Aboriginal participants were eligible for inclusion if they were 50 years or older; Aboriginal participants were invited to enrol in the program if they were 35 years or older.

Data were collected for 258 participants using several health assessment surveys before starting the program, and every six months after. Qualitative data were also collected through semi-structured interviews at each stage of the program.

In the qualitative interviews, participants spoke about the program favourably. Through client-centred care planning and peer-led self-management groups, clients with chronic conditions said they had become more informed about their condition and more involved in their own health care. Participants reported that a significant impact of the program was the bringing together of people to share common concerns and to learn from each other. This enabled clients to better come to terms with their condition, which appeared to be an enabler for better self-management.

The results of the health assessments improved significantly over time, indicating that participants demonstrated improved understanding of their condition and improved their ability to manage and deal with the symptoms of their condition.

Quantitative analysis demonstrated that both GPs and participants reported that participants knew more about their condition following the program. Participants who completed the program also reported an improvement in general health and a reduction in pain compared with the beginning of the program. Hospital visits and visits to the GP decreased by 66% and 28%, respectively, over the course of the program.

Lessons learned

These results suggest that involvement in peer-led self-management education programs have a positive effect on patient self-management skill, confidence, coping and communicating with health care providers, as well as improving health-related behaviour.

Participants also enjoy improved overall health and wellbeing, and improved quality of life.

Health professionals commented that involvement in the program improved interdisciplinary collaboration, with positive benefits for clients in terms of clinical care.

Despite initial resistance, health professionals responded positively to the program when they saw the benefits for their patients and their own practice. This shows how important effective communication strategies are before, during and after project implementation.

This program was not able to demonstrate benefits for Aboriginal patients. The Stanford Program has been adapted for use in Aboriginal and Torres Strait Islander communities. Work to develop a suitable model for Aboriginal and Torres Strait Islander peoples is discussed in *Implementing the Flinders Model of Self-management Support with Aboriginal People who have Diabetes: Findings from a Pilot Study*.

Wider relevance

The importance of supporting patients to self-manage is being increasingly recognised in clinical practice, in academia and in health policy. International and domestic studies have demonstrated the clinical effectiveness of this approach.

The current focus of the health system on acute and episodic care is clearly unsustainable and additional effort and funding is required to establish systems that promote self-efficacy, self-management and wellness rather than the current illness models of care. A change in the culture of medical practice is required but can be achieved.

This case study has demonstrated that CDSM and SMS is feasible in rural areas. Wider implementation will require a comprehensive education program aimed at individual patients and their family, health services and individual health professionals.

People suffering chronic conditions can be overwhelmed by their health problems. They may be discouraged that they will develop complications, or they may be struggling to cope with other personal and family issues. International research shows that when patients and their general practitioners (GPs) and other health care providers set goals together, and when patients gain management skills in a peer-led group, their knowledge and confidence increase, their health and quality of life improves, and they use fewer health services.

This South Australian pilot replicated these findings, demonstrating that best practice in chronic condition management can succeed, even in rural areas with shortages of health professionals, busy GPs and smaller numbers of potential participants.

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